INSPPIRE-2

Summer Newsletter

The **In**ternational **S**tudy Group of **P**ediatric **P**ancreatitis: **I**n search for a cu**RE** (INSPPIRE)

Summer | Issue 3 | August, 2021

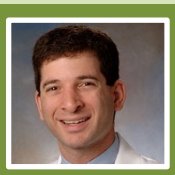
Our Team: 26 Centers Worldwide- Meet Our Southern Teams

Consortium for the Study of Chronic Pediatric Pancreatitis and Diabetes and Pancreatic Cancer (CPDPC)

Identifying the cause and progression of acute recurrent and chronic pancreatitis and how it affects patients and their families. We are looking for treatment options for these children to improve their quality of life.

The INSPPIRE 2 study is recruiting children with acute recurrent and chronic pancreatitis from all corners of the United States, Canada, Israel, and Australia. In this newsletter, we are highlighting our sites in the Southern United States. Please see below for contact information.

Baylor College of Medicine
Texas Children's Hospital, TX

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Associate Professor
Co-PI: Dr. Wenly Ruan
SRC: Laurel Cavallo, Cynthia Tsai
CRC: Diego Olvera, Tianta' Strickland
Tel: 832-824-7458

University of Texas Southwestern Medical Center, TX


Site PI: David Troendle, MD
Associate Professor
Co-PI: Megha Mehta, MD
CRC: Stephanie Timsah, Brittany Mann,
Tel: 214-456-8000

Ochsner Hospital for Children
Louisiana, LA

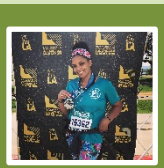

Site PI: Matthew Giefer MD
Co-PI: Ryan Himes MD
Nurse Coordinator: Michelle Rousset RN
CRC: Shawan Stewart
Tel: 504-894-2873

The Pancreas Programs at our Southern sites provide specialized care for children with pancreas disorders. We offer organized, coordinated and efficient means to find out if kids have pancreatitis and to treat them. We closely work with pain, endocrinology and surgery teams to provide the best of patient care.

Children's Hospital of San Antonio
Christus Health, San Antonio, TX


Site PI: Javier Monagas, MD
CRC: Katrina Roberts
Sarahi Fermaintt, Lab Scientist
Terriel Newsom, Research Nurse Coordinator
Bridget Medina, Regulatory Coordinator
Rebecca Hammack, Regulatory Coordinator
Rosario Ocampo, Research Director
Mary Sueltenfuss, Research Nurse Coordinator

Emory University School of Medicine
Children's Healthcare of Atlanta, GA

Site PI: A. Jay Freeman, MD
Associate Professor
CRC: Angela Stallworth
Pancreas Program Nurse and Coordinator: Kara Nash
Tel: 404-712-4846

https://medicine.uiowa.edu/pediatrics/research/pediatric-centers-and-programs/insppire-pediatric-pancreatitis-research-project

Watch your inbox!

Seattle Children's and the University of Iowa invite you to complete a survey! We want to help youth reduce the impact of pain in their lives by learning more about pain, health, and medication use in youth with pancreatitis and their parents/families. **If you receive an email with the subject "Pediatric Pancreatitis Survey Study (INSPPIRE2)" or similar, please click the link to learn more about the study and participate.** Parents who complete the survey earn a $15 Amazon.com gift card, and youth who complete the survey earn a $10 Amazon.com gift card.

Web-MAP CP Study

Do you have chronic pain?

Seattle Children's is doing a study looking at pain management in children with pancreatitis between the ages of 10-19 years. If you are interested in taking part in this study to help find ways to deal with your pain please contact palermolab@seattlechildrens.org or call the research staff at 253-987-6105 or toll free 1-855-932-6272.

Frozen Watermelon "Popsicles"

Ingredients:

Small seedless watermelon

Instructions:

1. Cut across the watermelon to make wedges about 1 inch thick

2. Carefully cut a slit into the rind of each wedge and put a popsicle stick into each slit.

3. Arrange the wedges on a baking sheet so they are not touching.

4. Freeze until firm , at least 3 hours.

Nutritional information per serving: Calories 40, Total Fat 0g, Total Carbohydrate 11g, Sugars 9g, Protein <1g.

Reference: Healthy Family Recipes for Pancreas Disease, The National Pancreas Foundation 2021

Mark E. Lowe, MD, PhD

Harvey R. Colten Professor of Pediatric Science
Washington University School of Medicine

Pancreatitis and Genetics

Q: Do genetic factors play a role in ARP or CP?

A: In children, genetic risk factors play a large role in the development of ARP and CP. Genetic risk factors are changes or mutations in a gene. By themselves, they do not cause ARP or CP, but along with other risk factors, they increase the child's risk for developing disease. Thus, many children who have the same genetic mutation do not develop ARP or CP. The majority, perhaps as many as 75%, of children with ARP or CP have a genetic risk factor. Some children have more than one genetic. We do not understand the other factors that cause one person to have ARP or CP and another, with the same genetic mutation, to never develop pancreatitis. Through our research in INSPIRRE, we hope to identify genetic and other factors that contribute to disease.

Q: What are the genes associated with ARP and CP?

A: The list grows longer with time. The most common genes are PRSS1, CFTR, SPINK1 and CTRC.

Q: How do these genes affect pancreas function?

A: All of the known genes that confer risk contribute to the digestive or exocrine function of the pancreas. They make proteins that digest dietary proteins and fats or that regulate water and bicarbonate secretion. How the mutations in these genes cause disease is not understood. Many researchers are now trying to define the mechanisms by which genetic mutations cause ARP and CP. Greater knowledge will lead to novel, effective therapies for these disease.

Q: Is there anyway to slow down or prevent more pancreatitis attacks?

A: Unfortunately, for most there is no therapy that will predictably slow down or prevent more pancreatitis attacks in children. Through INSPIRRE, we have learned that most children who have CP started with ARP. Because some children have causes for their disease that can be helped by medicines or surgery, the attacks and progression to CP can be stopped in these patients. That's why it is important to fully evaluate everyone for known causes of disease. We don't yet have therapies for patients with genetic risk factors yet, but once we do there is hope that the progression to CP can be stopped in them as well.

Q: Is gene therapy available?

A: Gene therapy is not available for pancreatic diseases although it is an option that needs to be pursued. Another approach is to help the mutant protein behave more normally. This approach has been used successfully in patients with cystic fibrosis. They have mutations in the same CFTR gene that increases risk for ARP and CP. It is possible that the medicines used in cystic fibrosis could stop or slow down pancreatitis attacks in patients with CFTR risk factors.